IMPLEMENTATION OF COMPREHENSIVE SCREENING FOR CERVICAL CANCER IN CANADA: IMPEDIMENTS AND FACILITATORS

Gavin C.E. Stuart, MD, FRCSC,[1]
Jean Parboosingh, MB, ChB, MSc,[2]

[1]*Professor and Head,*
Department of Oncology,
University of Calgary,
[2]*Senior Medical Consultant,*
Disease Prevention Division,
Health Canada,
Ottawa, Ontario

ABSTRACT

Cervical cancer screening has been available in Canada for over 50 years, and numerous task forces and workshops have recommended that organized screening programmes should be implemented. Despite this, the majority of screening in Canada take place in an opportunistic fashion and cervical cancer still occurs in 1996. This paper describes the history of screening in Canada and the current activity at provincial and national levels. It also identifies the impediments to the development of comprehensive screening programmes as recommended over the years. Factors which can act as facilitators to the implementation of such programmes and the role of physicians in achieving them are also identified. Currently, at a national level, a Cervical Cancer Prevention Network has been formed. This is an informal association of provincial and federal health department representatives with the College of Family Physicians of Canada, the Canadian Society of Cytology, the Society of Obstetricians and Gynecologists of Canada, the Gynecologic Oncologists of Canada, and the Society of Canadian Colposcopist. The purpose is to facilitate the development of quality organized screening programmes in all provinces and territories.

RÉSUMÉ

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Le dépistage du cancer du col est offert depuis plus de 50 ans au Canada, et de nombreux groupes de travail et ateliers ont recommandé la creation de programmes de dépistage structurés. Malgré cela, le dépistage est surtout effectué de façon opportuniste et le cancer du col survient encore en 1996. Dans cet article, on fait l'historique du dépistage au Canada et on décrit les activités menées actuelllement aux paliers fédéral et provinciaux. Les obstacles à l'élaboration de programmes de dépistage exhaustif, qu'on a recommandée au fil des âns, y sont aussi décrits, de même que les facteurs qui peuvent faciliter la création de ces programmes et le r6le des médecins pour parvenir a cette fin. À l'échelle nationale, on vient de créer un Réseau de prévention du cancer du col. Il s'agit d'une association informelle de représentants des ministères fédéral et provinciaux de la Santé, ainsi que du Collège des médecins de famille du Canada, de la Société canadienne de cytologie, de la Société des obstétriciens et gynécologues du Canada, de la Société des gynécologues oncolgistes du Canada et la Société canadienne des colposcopistes. Le Réseau vise à faciliter l'élaboration de programmes de dépistage structurés et de grande qualité dans toutes les provinces et tous les territories.

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INTRODUCTION

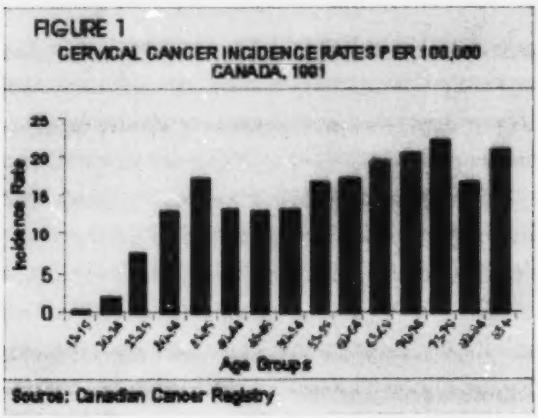
The rationale for the International Symposium. Physician Participation in Comprehensive Programmes for Screening for Cancer of the Cervix, at the 1996 Annual General Meeting of the Society of Obstetricians and Gynecologists of Canada (SOGC), was to demonstrate that Canada is not alone in revisiting the issue of cervical cancer screening. Besides the United Kingdom and Canada, other industrialized countries including Australia, the Nordic countries, and Europe as a whole are also currently reviewing their cervical cancer screening activities.[1-3] The United States Public Health Service has established a National Breast and Cervical Cancer Screening Early Detection Program to provide breast and cervical screening services to underserved women, particularly those of low income, racial/ethnic minorities, and older women.[4] This paper will provide an overview of the activities in Canada that have

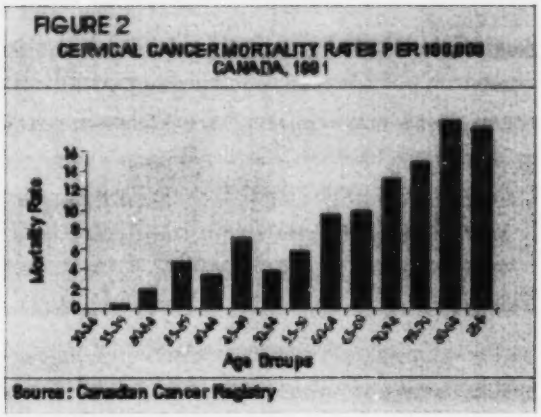
been undertaken over the years to reduce the morbidity and mortality of this preventable cancer, and the role of the physician in overcoming the barriers to the implementation of comprehensive programmes in each of the provinces.

Amongst providers of health care in Canada, and specifically within the community of obstetricians and gynecologists, there is an awareness of the value of screening for cervical cancer that has promoted widespread use of opportunistic screening. Our understanding of the disease process at a biologic level is expanding rapidly, and current disease concepts would suggest that this disease is preventable in its invasive form. In Canada, the majority of cervical cytology smears are obtained by physicians at either a primary care or consultative level. Yet new cases of invasive cervical cancer continue to occur; in 1996, it is estimated that there will be 1,350 new cases of cervical cancer and 390 deaths.[5] Why, therefore, has a programme of screening not been implemented in each province in Canada that would have as its goal, the elimination of invasive cervical cancer?

MORBIDITY, MORTALITY, AND SCREENING PRACTICES IN CANADA

Over the past three decades, there has been an overall reduction in the age-standardized mortality rates from invasive cervical cancer from 7.4 per 100,000 females in 1969 to 2.4 per 100,000 females in 1992, and a reduction in incidence rates from 21.6 per 100,000 in 1969 to 10.4 per 100,000 in 1990. However, since the mid-'70s, the rate of decline in incidence rates has slowed, particularly among women under 50 (Laboratory Centre for Disease Control; unpublished data).





Figures 1 and 2 show incidence and mortality rates by five-year age groups for Canada in 1991. Nevertheless, it must be acknowledged that today we have one of the lowest rates of cervical cancer in the world.

The burden of the disease on women and the health care system also can be demonstrated by the large number of smears taken per year and the subsequent follow-up of abnormal smears. Using data from national and provincial surveys, Goel estimated that more than four million smears were taken every year in Canada, of which approximately eight percent or over 325,000 will be abnormal (Goel V. Developing a Business Case for Cervical Screening Information Systems. Unpublished report to Disease Prevention

Division, Health Canada, 1995).

In spite of the known benefits of screening, an important proportion of women do not have Pap. smears taken and this number has increased in recent years. The Health Promotion Surveys of 1985 and 1990 reveal that in 1990 twice as many women in the 25 to 44 age group reported never having had a Pap. smear than in 1985; and, in 1990, 27 percent of women over 65 had never been screened.[6] Studies in Canada have revealed that almost half of the newly diagnosed cases fall into the category of "no cytology or cytology longer than five years ago," and that women who were most at risk had one or more of the following characteristics: a low level of education, neither of the official languages as a mother tongue, were native, a recent immigrant or aged over 60.[7-9]

Besides ensuring that physicians encourage these women to be screened, there are other factors that need to be addressed in order to reduce the number of cases of cervical cancer. These include the inadequacy of smears as a result of improper technique in taking or preparing the smear, undercalls by cytotechnologists, and inadequate follow-up or *loss to* follow-up. The solutions to these issues lie in the development of comprehensive organized screening programmes with quality management, information systems, and professional and general education to raise awareness among the public and to inform physicians of the need for a structured approach to cervical cancer screening.

CERVICAL CANCER SCREENING IN CANADA: AN HISTORICAL PERSPECTIVE

Screening in Canada began in British Columbia in 1949 and gradually spread across the country. In 1973, the Conference of Deputy Ministers of Health convened the Walton Task Force to review the need to develop comprehensive screening programmes for cancer of the cervix. The Task Force recommended that health authorities support the development of such programmes and that all women should be encouraged to participate. Recommendations also pertained to quality assurance in cytology and to screening interval, follow-up mechanisms, provincial registries, and uniform terminology. [10] However, a 1980 survey assessing the effects of the Task Force showed that, in the main, the provinces had not implemented the recommendations.[11] The Task Force was, therefore, reconvened in 1980 and again made recommendations related to the frequency of screening, laboratory quality control, and follow-up. Improvement in the quality and sensitivity of screening programmes, recruitment of unscreened women, and the development of screening registries were seen as essential components of an effective system and as likely to be more effective than attempting to increase the frequency of screening. [12] In November 1989, participants at a National Workshop on Screening for Cancer of the Cervix reviewed the 1982 recommendations and recognized that programmes in Canada still were not fully effective. It was noted that not all women at risk were being screened, some physicians did nor have the skills to take satisfactory smears, some laboratories were too small to provide appropriate experience for staff and did not have adequate quality control mechanisms in place, and some women with abnormalities were receiving inadequate follow-up and treatment. On the other hand, some women were having smears taken more frequently than necessary, thereby using resources inappropriately. The twenty-seven recommendations made at the workshop included: the need for an organized approach; the frequency of screening; the management of abnormalities; information systems; and training and quality control requirements for laboratories and programmes. [13]

The Society of Obstetricians and Gynecologists of Canada, the Gynecologic Oncologists of Canada, and the Society of Canadian Colposcopists supported the recommendations made at this Workshop and the development of formal programmes for cervical cancer screening. However, they recognized the need for the recommendations to be considered as a whole and for partial implementation not to occur unless comprehensive programmes existed within the provinces. In particular, the recommendation for a screening interval of three years was of concern if high-quality laboratory services and adequate information systems

were not available to ensure that women were recalled in a timely fashion. These societies also were concerned with the recommendation that repeat smears without colposcopy were adequate follow-up for lowgrade squamous intra-epithelial neoplasia. These groups suggested that until information systems and high-quality cytology services were in place, annual screening of at-risk women should continue to be the standard of practice.[14]

IMPLEMENTATION OF SCREENING PROGRAMMES IN CANADA

Although cervical cancer screening has been well accepted, opportunistic screening has been the predominate approach, and the implementation of comprehensive provincial programmes has been slow. The earliest provincial screening programme to detect pre-invasive cervical cancer in Canada was started in 1949 in British Columbia. Today, this incorporates a central laboratory as well as a colposcopy programme for the management of pre-invasive lesions. In 1991, Nova Scotia introduced an organized, accountable, provincial screening programme in response to the recommendations of the three national task force reports. Other provinces and territories have been addressing this issue and are at various stages of developing some or all components of an organized programme. However, a model of a fully implemented comprehensive provincial screening programme does not yet exist.

The two provinces, British Columbia and Nova Scotia, with the most well developed programmes are focusing currently on improvements to their information systems that will allow for the recruitment and recall of women and an enhancement of their quality assurance programmes. Since October 1993, in Ontario, a Cervical Cancer Ad Hoc Working Group, representing the Ontario Medical Association, the Ontario Association of Medical Laboratories, and the Ontario Cancer Treatment and Research Foundation, has been meeting to consider ways to improve the current system of cervical screening. The provinces of Alberta, Manitoba, New Brunswick, Newfoundland, Prince Edward Island, and Saskatchewan *are at* various stages in the process *of* implementing comprehensive screening programmes. Prince Edward Island has developed a sophisticated information system to facilitate programme management and evaluation. Quebec will be addressing, the issue of cervical cancer in the near future.

IMPEDIMENTS TO AND FACILITATORS OF THE DEVELOPMENT OF COMPREHENSIVE PROGRAMMES

A number of factors has impeded the development of comprehensive programmes and, thus, the reduction of new cases of invasive cervical cancer, but there are also means of promoting this concept from the perspective of the practising obstetrician/gynaecologist and, indeed, all primary care physicians within the Canadian health care context. As the slow-down in the rate of reduction of new cases demonstrates, the opportunistic approach has probably reached its limits and we need to address this problem in a more comprehensive manner.

Perceived impediments are seen in four specific areas. The most significant of these relates to recruitment to a programme. Within each province, there continue to be identified underserved populations amongst whom the risk of disease remains high.[8] Even in British Columbia where organized but not comprehensive screening programmes have been in existence for nearly four decades, there remain aboriginal populations with higher incidence rates as well as mortality rates than the general Population.[7] Review of the relevant literature confirms that the major factor in the development of invasive disease is the failure ever to have been screened. This group of women is comprised of two subsets: those who have been within the health care system for any reason and have not been screened and those who have never contacted the system. The former subset represents "lost opportunities" and reinforces the need for all providers, but particularly primary care providers and consultant obstetricians and gynecologists, to promote actively the need to

consider screening within each health care encounter. A physician's recommendation to a patient to have a Pap. smear taken is a powerful tool to increase the uptake of screening.

The second subset is made up of those women who have not been identified as a part of the target population. Essentially, in order to screen those women identified as "at risk,," a population-based data set is required to use as a denominator for a comprehensive programme. This is affected considerably by prevailing- Provincial/Territorial legislation. Some provinces have extremely permissive legislation in place that facilitates not only the identification of the population at risk but also provides linkage with service codes that will generate screening rates for the population. Other jurisdictions have legislation that allows for such population-based registries only in a research setting or within tightly defined circumstances. The issues of confidentiality and freedom of information are highly relevant. It is likely that practitioners will have considerably more influence in the effort to increase opportunistic screening in the first subset of women, but they should also support other efforts to establish a population-based database. If the population at risk can be identified, other strategies including the concept of "patient rostering" which is effectively employed in other countries may be invoked to ensure penetrance of the programme. This would be highly relevant to primary care physicians.

The second major impediment involves the lack of integrated information systems necessary to support a comprehensive programme. Although this requires the database previously referred to for the purpose of "call-recall," it also requires that a system will allow access for the practitioner to retrieve past cytologic screening history. Ideally, the same system would ensure linkages with the database that would record the management of pre-invasive disease and invasive cancer. For the gynaecologist, this would include follow-up information on abnormal smears, colposcopy results, and a record of appropriate management. This issue is inseparable from the legislative restrictions on health care information described earlier. There are already several dynamic software packages available for population-based cervical cancer screening support within Canada. It is not practical to expect the practitioner to develop this system, but such efforts should be supported and assistance given in determining the recorded data elements and appropriate access. It has been demonstrated previously that a minimal data set is more effective than an all-inclusive structures.[15]

The third impediment to a comprehensive screening programme has been the lack of nationally agreed-upon quality management guidelines. Many documents have been published within Canada over the past two decades with recommendations or opinions. There is a need, however, to ensure that there is a coordinated approach integrating all components of the programme. Examples of this need include the lack of an agreed-upon set of performance indicators for a programme, the lack of consensus on screening intervals, the inconsistency of recommendations for the management of abnormal cytology, and the diverse reporting terminologies in use. This is an area in which the national speciality societies are now actively collaborating to provide these components to a comprehensive programme. Thus, primary care providers should have access to consistent guidelines for obtaining a smear, recall intervals, ind follow-up of abnormalities. Cytopathologists should be able to use integrated guidelines for laboratory quality control, reporting terminology, and recommendations. Gynecologists should have agreed-upon guidelines for colposcopy, treatment, and follow-up. Oncologists should be able to provide quality management guidelines for staging, treatment, and key outcome indicators.

The fourth area of concern relates to the role of the provider in a comprehensive programme. Most cytology smears are obtained currently by physicians in this country. However, many of the identified "hard-to-reach" populations might require a strategy involving such alternative care providers as nurses, trained health care workers or other such individuals. This strategy has been used very effectively in the Northwest Territories. However, even with the primary care physician as the "pivot" comprehensive screening can be facilitated by inherent rewards within the system for physicians who are able to increase

penetrance of a population by considering these alternative providers and seeking innovative methods. Such incentive programmes in the U.K. have been reported to be successful in increasing the proportion of the population screened.[16] The objective of a comprehensive programme should be to ensure that the entire target population is appropriately screened, and professional roles should facilitate rather than limit this.

Despite the failure to provide a comprehensive screening programme, Canada has been able to reduce the incidence and mortality of invasive cervical cancer significantly by using widespread opportunistic screening. Four significant promoters at key points in the health care system can be identified. Perhaps the most pivotal of these points is at the level of consumer input and the focus on women's health as a key issue in improving the health of the population. This involves identifying cervical screening as an issue in a setting of multiple health issues competing for priority. These include abuse, alcoholism, and child health, and giving women at risk the right to integrate screening behaviours into their health practices. In the domain of cervical cancer screening, the role of the physician should be to provide support to the women promoting the issue of cervical cancer screening.

Secondly, at a federal level, Health Canada has promoted the coordination of cervical cancer screening, through the convening of Task Force meetings in 1976, 1982, 1989, and most recently at Interchange '95, held in Ottawa on February 27 to March 1, 1995 in an attempt to identify the status of the implementation of comprehensive provincially-based cervical cancer screening programmes and the factors impeding their development. The proceedings of the Workshop have been published and include information on the status of provincial activities in 1995.[17] Recommendations have been made and consensus has been achieved in several major areas over the years.

Thirdly, national speciality societies, and specifically the Society of Obstetricians and Gynecologists of Canada, have been instrumental in education to identify the importance of screening, in the development of guidelines for the management of pre-invasive and invasive disease, and in advocacy for the health of women. In the past five years, the SOGC has published guidelines for the management of the abnormal cytology smear, colposcopy, and the management of invasive cancer of the cervix. These steps are critically important but will fall short of achieving the goals of a comprehensive programme if not coordinated with population needs, monitoring and surveillance methods, information systems, and the recommendations of many other speciality groups. Although in excess of 90 percent of women in a screening programme will have no need for further intervention, it should be the role of the gynaecologist to ensure that appropriate management is offered to the small minority requiring further care. It is likely in this context that obstetricians and gynecologists will continue to have maximal input.

The fourth promoter includes other national organizations committed to a reduction in the burden of cancer. The National Cancer Institute of Canada in partnership with the Canadian Cancer Society has demonstrated actively the need for comprehensive screening, and has sought to assist the Provinces and Territories in implementing such programmes. In March of this year, a Workshop was convened to address the recruitment of the underserved with several strategies and action steps described. Although these activities involve in large part the expertise of physicians, other key roles include those of the epidemiologists, the behavioural scientists, the statisticians, the systems analysts, and health care providers. Each of these individual contributions to the development of a comprehensive screening programme will advance the implementation of such within the provinces.

Even though these impediments and promoters may be identified, there are many related issues in the health care environment both at a *consumer and pro* fessional level that may influence the role of the physician. Reference has already been made to the potential disjunction of national policy and provincial implementation. There are many competing health care needs in the population at risk that require the attention of the primary care provider. Professionally, there are interdisciplinary coordination *issues*

*requiring reso*lution. Screening cytology must be distinguished from diagnostic or follow-up cytology. A consistency in standard terminology for cytology reporting, diagnostic evaluation, and definition of performance indicators is not present and is highly desirable. The environment to support and reward innovative and alternative means of increasing the *proportion of* women being screened developed by the primary care physician must be provided to allow for further reduction in the incidence of invasive disease.

THE CERVICAL CANCER PREVENTION NETWORK

At the end of Interchange '95, participants agreed to continue to meet, and requested that the federal government continue to facilitate the exchange of information between the provinces, and provide direction and leadership in the area of standards and quality of care. As a result, the Cervical Cancer Prevention Network, an informal association of provincial and federal health department representatives with the relevant clinical professional bodies, is evolving. Clinicians represented include members of the College of Family Physicians of Canada, the Canadian Society of Cytology, the Society of Obstetricians and Gynecologists of Canada, the Cynaecologist Oncologists of Canada, and the Society of Canadian Colposcopists.

Further progress in Canada to prevent cervical cancer should follow defined steps. The goal of a *compre*hensive screening programme, that is to reduce the mortality of cervical cancer, must be kept in the forefront. The principles of such a programme must be articulated to include the proven effectiveness of cervical screening, that there are still large groups of women not screened, that most primary care in Canada is provided by physicians, and that there are still no provincial information systems to support appropriate recruitment. The initiative must be to improve the health of women in Canada, but leadership to achieve this must be derived from the physicians who are providing the care.

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